

## Living with Amyotrophic Lateral Sclerosis

*By Jim Petersen*

“  
**My speech was slurred, but understandably when I gave that blessing.**  
”

It was the autumn of 2002, and it seemed that all of nature was in full color dress for the upcoming holiday season. In keeping with the season, my wife Nancy and I were making plans for a traditional Thanksgiving feast with our family and loved ones to thank Almighty God for our bountiful blessings. My speech was slurred, but understandable, when I gave that blessing.

From that time on, my speech continued to worsen and the tendency to choke on the simplest food became a concern so we visited our family internist. It was thought that I had experienced a mild stroke. ALS is difficult to diagnose because it mimics so many other ailments. After seeing a number of specialists, I was finally referred to KU Medical Center Neurology Clinic, which collaborates with The Keith Worthington Chapter of ALSA. It was here that I was diagnosed with ALS.

An immediate and drastic change took place in our lives. We had been foster parents to some 400 children over the past 30 years. ALS put an end to that portion of our lives. Instead of caring for foster children, we joined with others to form a corporation to serve children in a different way. *MID-AMERICAN CHILDREN'S SERVICES, INC.* endeavors to meet the basic needs of less fortunate children and their families by collecting items discarded by those more fortunate and distributing them to the neediest in our community.

On an intimate and more personal note, day-to-day communication with my spouse of nearly 57 years is nearly impossible. She helps dress me, keeps me on schedule, drives me to numerous appointments ... in short, she is my lifeline.

Because I am a veteran of WWII, The Veteran's Association has been generous in supplying some of the medications prescribed by doctors at KUMC.

Without the support and encouragement of the wonderful staff at The Keith Worthington Chapter, Nancy and I would be desperately searching for ways to cope with the ever changing needs brought on by this dreadful disease. First it was trying to manage nutrition. ALSA came through with suggestions for pureeing some of the softer table foods.

*(Continued on page 2)*

### Upcoming Events . . .

June 11: Big Dog Motorcycle Tornado Rally in Wichita



July 16: *Getting There to Fight ALS*- Airplane, Motorcycle & Car Show in Wichita

July 18: Pro-Am Golf Tournament at Wichita Country Club

Walk to d'feet ALS: check [www.alsamidwest.org](http://www.alsamidwest.org) for your city's date and location!



## Chapter Happenings



### FROM THE NEBRASKA OFFICE

U.S. Senator Ben Nelson of Nebraska will be chair of the Omaha Walk to d'feet ALS on Friday, September 30th, at 6:30 p.m. in Elmwood Park. Former Nebraska Secretary of State Scott Moore, who works in government relations for Union Pacific Railroad, will serve as co-chair. Scott's mom, June Moore of Stromsburg, NE, has ALS. Erin Thomas of Fort Calhoun, whose husband, Craig Thomas, is 28 years old and living with ALS, have established Omaha's first online team for 2005!

The Columbus Board of Realtors, headed by its president, Rita Ingold, will chair the September 25th Columbus, NE, Walk to d'feet ALS. The realtors are forming a large Walk team. The Columbus Walk is Sunday, September 25th, at 2 p.m. at Pawnee Park.

The Grand Island Walk to d'feet ALS will be headed up by "The Crew," friends of John Brownell, a Grand Island attorney who is affected by ALS. The Crew is led by Michael Gloor, CEO of St. Francis Hospital. The Walk will be at Eagle Scout Lake at 2 p.m. on Sunday, September 18th.

Phi Delta Theta of the University of Nebraska at Lincoln, whose philanthropy chair is Ben Johnson, will kick off a university wide Walk with meetings at the 44 fraternity and sorority houses during the first week of school in the fall. The Lincoln Walk to d'feet ALS is Saturday, September 24th at 10 a.m. just east of the football stadium. (The 24th is an OFF football date.)

The Creighton Phi Deltis will host their annual "A Night at Lou's ALS Benefit Concert" on Friday, September 24th at Omaha's Soko! Hall. The national act Swizzletree is headliner. Daniel Reznicek, philanthropy chair, and about 80 of his fraternity brothers welcomed guest speaker Craig Thomas of Fort Calhoun at their meeting last month.

### FROM THE WICHITA OFFICE

It is not too early to get your team registered now for the Walk to d'feet ALS walks! Register your teams online at <http://support.alsa-midwest.org/site/PageServer> today. Building a team website allows you to e-mail letters to family and friends and to track your team's progress with real-time donor recognition. Log on now to get your team started!

Volunteers needed: June 11 & 12, for the Big Dog Motorcycle Tornado Rally, Wichita, Kansas. We will have a booth & poker run at this event that is expecting 7,000 to 10,000 motorcyclists. Volunteers are needed to work the ALS booth Saturday from 9:00 am to 11:00 pm and for the poker run, Sunday, June 12th in the afternoon. Please contact Kathleen Willie for more information at (316) 612-0188 or email at [Wichita@alsa-midwest.org](mailto:Wichita@alsa-midwest.org).

### FROM THE SPRINGFIELD OFFICE

It was a great day for golf at the annual James F. Wiley Golf Tournament held on May 1, 2005 at Deer Lake Golf Course in Springfield Missouri. Mr. Wiley was a founder of Deer Lake. We have been chosen as the charity for next year, too. There were 16 teams with one pro and 3 amateurs per team.



The Jack Kramer Memorial Basketball Tournament will be held on September 24th at The Courts. Teams are \$100 with a \$5 donation at the door. Team registration will be available online in the near future. There will be an "Awesome Auction" with Sponsorship Opportunities available for the event. Call Valerie at 417/886-5003 for more information!

### FROM THE KANSAS CITY OFFICE



Folks from Richmond and surrounding towns gathered at the beautiful 100 year old refurbished downtown theatre for ALS Night in Richmond. The evening was organized by Leamon and Terry Johnson whose son, Mark, has ALS and is active with the Georgia ALSA Chapter. Mark was in town for the event. The Richmond High School senior drama students performed Lou Gehrig ~ The Luckiest Man. Proceeds from the event benefit the Keith Worthington Chapter.



## Support Group News

*For those affected by ALS, these support groups provide a forum to share information and practical experience, a safe place to allow emotions to speak, an educational gathering spot where speakers and caregivers address subjects of major interest, and a place to witness firsthand the constant miracle of people continuing to live productive fulfilling lives in spite of having ALS.*

---

### MISSOURI

The Jefferson City support group met on April 6th with 14 attending. There were new patients and caregivers attending for the first time. The group discussed several topics including current research and medications for ALS. The Jefferson City Group started back in February and will meet the 1st Wednesday of every other month (even numbered months) at 1:30 p.m. at Southridge Baptist Church, 1815 Veith Drive, Jefferson City, MO.

The Springfield support group met on April 12th with 12 attending. Registered Dietitian Mary Duff spoke on nutrition for ALS patients. After speaking, Mrs. Duff made smoothies for everyone to sample.

The Joplin support group, which has started meeting again, met April 27th with 9 attending. The group spent time talking about the disease and topics of interest for future meetings which will be held the 4th Wednesday of every month at 1:30 p.m. at the South Side YMCA, 3404 Mcintosh Circle, Joplin, MO.

A Columbia support group has been formed and will meet the 1st Wednesday of every other month (odd numbered months) at 1:30 pm at Tiger Place, 2910 Bluff Creek Drive, Columbia, MO.

A Branson support group scheduled its first meeting on May 18th. This group will meet the 3rd Wednesday of every month at 1:30 p.m. The location will be Faith Lutheran Church, 221 Malone Street, Branson, MO.

### NEBRASKA

Eleven people attended the April Columbus support group. The video "Maintaining Quality of Life: A Patients Perspective," was viewed and it led to a discussion of various equipment and adaptive devices that are available.

Eighteen attended the April Omaha support group meeting. Steve Langan was introduced to the group for the first time and presented everyone with information on past events and future ones that he is working on, including the Walk to d'feet ALS. Steve and Craig Thomas also shared that they presented information on ALS to the Phi Delt at Creighton University. The Phi Delt have had a concert the last few years to benefit ALS and have been involved with our Omaha Walk. The group then watched the second half of the video presentation from Dr Carlayne Jackson on "Current ALS Management: A Cocktail of Potential Therapies." A group photo was taken after the video.

### KANSAS

Seven were in attendance at the Hutchinson support group held at the Grace Episcopal Church on Wednesday, April 6th at 2 p.m. There was an interesting discussion following the viewing of the film "Preserving Emotional Health: Hopeful Insights From A Caregiver's Perspective" by Terry Wise, J.D. This brought home the idea that even if one feels that physically he can manage everything in an ALS patient's care, there is a possibility that this may not be the case from an emotional or psychological point of view.

The Wichita support group was held in the Grace Presbyterian Church parlor on Thursday evening April 7th with 15 in attendance. We had a doubly interesting evening because the principal speaker was Karen Stutzman, MS, RD, LS, CDE from the Via Christi system who spoke about "Why Good Nutrition?" and its relationship to the exacerbation of ALS. There were many good tips about increasing caloric content of foods without increasing the volume.

---

## Research Update - From ALSA's National Office

### More Evidence for Promise of Gene Silencing: Another Team Funded

April 25, 2005 by The ALS Association Reports Success in Mouse Model of ALS

**QUICK SUMMARY:** An additional report of success with a new gene silencing technique quickly follows prior positive findings with the approach in an animal model of ALS (amyotrophic lateral sclerosis), and lends further hope for rapid progress to clinical application.

A new approach to a therapy for ALS, also referred to as Lou Gehrig's disease, has added muscle strength and life span in animal models of the disease. The gene silencing approach, called RNA inhibition, prevents a specific gene from making its protein. The target is the enzyme called SOD1. This mutation appears in some cases of inherited ALS. The fact that two separate teams working toward an ALS therapeutic have recently reported similar hopeful findings with RNA silencing strategies shows that the approach indeed has promise

for rapid progress into clinical application, said Lucie Bruijn, Ph.D., science director and vice president of The ALS Association (ALSA).

Scientists have created mice that have the mutant SOD1 and also show symptoms remarkably similar to all types of ALS. Mice with the SOD1 mutation show better grip strength if treated with the RNA therapeutic, according to the report online April 25 in the *Annals of Neurology*, by ALSA funded investigators Timothy Miller M.D. and Don Cleveland, Ph.D., of the Ludwig Institute at the University of California, San Diego, and collaborators. Rapid application of this technique to ALS investigation is part of ALSA's program to harness new methods toward changing the disease.

## Progress on Biology of ALS Reported at AAN Meeting Michael Strong, 2005 Essey Awardee, Speaks on Cognitive Changes in Lou Gehrig's Disease

May 5, 2005

By Roberta Friedman, PhD, ALSA Research Department Information Coordinator

[QUICK SUMMARY: Canadian researcher Michael Strong, M.D., winner of the 2005 Essey Award spoke in his acceptance speech at the April meeting of the American Academy of Neurology in Miami, on the current concepts of how ALS destroys the nervous system. Further reports at the meeting gave early hints toward new therapeutics, and included findings on quality of life in ALS, design of clinical trials for the disease, and highlighted progress on understanding the basic biology of the disease process.]

Richard P. Essey presented the 2005 Sheila Essey Award for ALS Research to Michael Strong, M.D. on behalf of The ALS Association (ALSA) and American Academy of Neurology (AAN). Strong received the award for his blend of clinical compassion and cutting edge research into the causes and potential treatments for amyotrophic lateral sclerosis (ALS).

A member of ALSA's national board of trustees, Essey noted in presenting the award to Strong that many investigators have been using the prize funds to help young researchers enter and contribute to the ALS field. In his acceptance speech at the AAN meeting in Miami, Strong discussed current concepts of how the disease destroys the nervous system and noted that it is hard to do justice to the huge amount of work going on in the area. He focused on the idea that ALS may be a collection of syndromes that manifest as a disorder of key proteins in the nerve cells. "Many reasons may be leading to the ultimate death of these cells. There are only so many ways a motor neuron can say it is dying, but many ways to get there," Strong said.

One important association in the disease coming to light in the past few years is that many patients show cognitive changes with ALS. These changes can be subtle, but they lead researchers to conclude that more than the motor neurons are attacked by the disease. This concept may broaden the arena for investigation into the basic nature of the degenerative changes taking place and could point to new treatment strategies.

Researchers find that about half of ALS patients show cognitive changes that can be classified as a fronto-temporal dementia. Fronto-temporal dementia involves personality change that can include excessive emotional and compulsive behavior. Strong suggested that more than 50 percent of ALS patients may show these mild to moderate cognitive changes.

Strong's research interests have converged on the protein called "tau" that is part of the inner scaffolding of the nerve fibers. Tau typically is deposited in brain as people age, but not in the frontal regions, so finding deposits of tau in the frontal lobes indicates something beyond normal aging is taking place.

Tau has been implicated in other degenerative diseases of the nervous system. But aspects of tau deposits in ALS are unique to the disease. The main structure of tau is the nervous system. But aspects of tau deposits in ALS are unique to the disease. The main structure of tau is preserved, but added portions to the protein are evident for the tau deposits in ALS.

Strong then spoke in detail about the different proteins that make up the inner scaffold of nerve fibers. The proteins and motor molecules that move cellular cargo along the fibers must meet the extraordinary demands of the extremely long extensions of motor neurons that connect to the muscles. The proteins that maintain nerve fibers are very organized arrays of precisely constructed proteins, all on a microscopic scale. If any one component is made in excess, the structures cannot self assemble properly and becomes disordered. The result inevitably appears to be a motor neuron disease.

Some researchers are gathering evidence for problems in forming the necessary balance of nerve fiber proteins in mouse models of ALS. One idea is that mutant SOD1 is interfering with the proper translation of gene instructions into protein. Another is that the abnormal protein deposits in the disease are producing an inflammatory response that cannot be modulated and kills the cells. Still another is that the cells are not able to handle the messages that they are receiving in a balanced fashion, and so they die. Strong suggested that these all could be different reasons for the same end result, a loss of motor neurons. The shared late consequence in ALS is death of the motor neurons, but there could be different reasons upstream for this loss.

Additional findings that are contributing to better understanding of ALS, reported at the 2005 AAN meeting in Miami, are detailed below.

### SOD1 Mutation's Toxicity

Studies reported in posters at the meeting show how the protein change in some inherited cases of ALS might be producing toxic effects. Han-Xiang Deng, M.D., Ph.D., working with Teepu Siddique, M.D., at Northwestern University, Chicago, found that two key sites in one mutated version of the SOD1 protein are crucial to toxicity. Changing these sites by replacing the responsible amino acids, in a transgenic mouse bearing the mutation, prevents SOD1 from forming abnormal deposits in their cells. The mice also do not show motor neuron disease.

In addition, Deng reported that stubborn clumps of SOD1 that do not dissolve in lab tests appear at both the inner and outer membranes of mitochondria, the organelles that power cell processes. Previously implicated in ALS, the mitochondria with these aggregates are swollen and visibly damaged. These observations support several published studies that show mutant SOD1 is associated with mitochondria. If researchers learn exactly what is toxic about mutated SOD1, they can work towards targeted therapy to correct the damage in the disease.

### Early Hints on New Therapeutics

Now that scientists recognize that mutant SOD1 is toxic, they are trying to lower its content inside cells. Wu-Yen Hung, Ph.D., working with Siddique's group, reported on six potential therapeutic agents for ALS tested in fibroblast cells from SOD1 mutant mice. The drugs are from a library of 2000 FDA approved compounds.

*Continued on page 6)*

(Continued from page 5)

Hung indicated that it is too early to discuss any particular drug, as data only reflect their ability to lower production of mutant SOD1 by the cells. It is a long way from a drug that works in cells in a dish to a therapeutic that is safe and effective. These researchers are looking for a wide range of categories of compounds that might be candidate treatments. They are now testing the candidates by treating live mice that have mutant SOD1. A drug that delays the onset of symptoms in the mouse or extends survival time would be a potential therapeutic candidate.

### Gene Protects Motor Neurons

Erik Piro, M.D., Ph.D. director of the ALS Center at the Cleveland Clinic, is collaborating with ALSA-funded investigator Michael Coleman, Ph.D., at the Babraham Institute in Cambridge, U.K., to study the effect of a gene that protects the nervous system in mouse models of motor neuron disease. The WldS gene mutation delays disintegration of the nerve fibers and prevents loss of function, as well as visible damage to the cell body of motor neurons in a model of motor defects. Grip strength was preserved in the presence of the gene, compared to Wobbler mice without the WldS gene. Two WldS genes were better at preserving grip than a single gene copy.

The Wobbler mouse model recreates some aspects of ALS. It is not a perfect picture of the disease, but can give some information that could be helpful for therapeutic strategy. Understanding how the WldS gene is protective in this mouse could point to therapeutic avenues for ALS.

### New Findings on VEGF

In talks following the presentation of the Essey award, Mohammad Saeed, M.D., working with Siddique's group and collaborators, reported on a search for variants of the gene coding for VEGF (vascular endothelial growth factor) in people to see if any varieties of the gene that can occur in populations of people might be a risk factor associated with ALS. One variant of the VEGF gene did appear more often in people with early onset of ALS, Saeed reported. It is possible that this particular version of the VEGF gene could be associated with increased risk for the disease. The researchers did not reproduce findings from Europe, reported in 2003, that a variant of the VEGF gene is linked with ALS, and others have also failed to replicate that association  
<http://www.alsa.org/news/article.cfm>.

### Quality of Life in ALS

Quality of life for ALS patients increases with use of multidisciplinary clinics according to a presentation given by Dutch researcher Leonard Van den Berg, M.D., of the Rudolf Magnus Institute for Neurosciences, in Utrecht, the Netherlands. The investigators conducted interviews of 208 patients and their caregivers. Of these patients, 75 received care outside of a specialized ALS center. Better mental health and social functioning appeared for those patients treated at the multidisciplinary clinics. Comment from the audience suggested that this kind of data is needed for U.S. patients to convince insurance companies that the multidisciplinary clinics. Comment from the audience suggested that this kind of data is needed for U.S. patients to convince insurance companies that the multidisciplinary approach is cost effective. ALS patients can receive care outside of a multidisciplinary clinic and maintain a high quality of life.

### Design of Clinical Trials for ALS

In another session devoted to clinical findings in ALS, Adam Czaplinski, M.D., working with Stanley Appel, M.D., at Baylor University in Houston, spoke to the use of database records from past ALS trials, as a cost effective alternate to concurrent control groups in clinical trials. Appel, a former Essey awardee, used the award funding to support Czaplinski's efforts. The strategy was to match ALS patients in a Baylor database, with the control patients who had been assigned to placebo in a prior clinical trial of the potential therapeutic, IGF-1.

The two groups of patients could be matched for characteristics such as age, sex, and initial clinical measures at the start of the trial. Czaplinski said that patients who progressed more slowly were likely to continue to do so. Those with more rapid deterioration at the start of study, also tended to have their disease continue to progress rapidly.

One limitation to mining a database for controls for new studies is that patients after 1999 are tending to progress more slowly in general and survive longer. Since the aim is to avoid exposing large numbers of ALS patients to ineffective therapy, a database instead of concurrent controls could work for pilot trials as a first step, but the definitive trial for any new ALS therapeutic approach will be still be a randomized, placebo controlled trial, Czaplinski concluded.

A way to follow patients during clinical trials is offered by a measure of nerve function called MUNE, motor unit number estimate. This estimate of how many nerves are working is made by recording electrical signals. Jeremy Shefner, M.D., Ph.D., State University of New York in Syracuse, reported in a talk at the meeting that MUNE has potential to serve as a marker of progression in ALS, in clinical trials and in animal studies of candidate treatments. Motor unit number estimation by electrophysiology correlated with onset and duration of disease in animals, Shefner reported. MUNE has too much variation to use as a measure of disease progression in a single patient, he continued, but MUNE could be a marker of drug effect in groups of patients in clinical testing.

### Seeing ALS Damage with MRI

Camilla Blain, M.D., part of a research team at Kings College, in London, U.K. working with Nigel Leigh, M.D., and collaborators, spoke about the use of a type of brain imaging that can look at changes in the bundles of nerve fibers within the brain and spinal cord. The magnetic resonance imaging, called diffusion tensor imaging, can tell by the signal from water molecules within the brain that the nerve tracts are intact or are damaged. The group studied 22 ALS patients and compared them to 24 control individuals. The ALS patients were different on scans compared to controls.

The ability to see changes in the nervous system as ALS progresses would be quite useful for clinicians and for testing therapeutics. But still at issue is the timing of such imaging. The typical delays to diagnosing ALS may leave patients too far along for imaging to be a realistic tool. Earlier use of imaging, earlier diagnosis, and better imaging techniques are all hopeful developments for the field.

# FOR SALE

## HOMES

Fully accessible to accommodate manual or electronic wheelchairs: 2 ramps (garage and outdoors), wheelchair accessible shower, oversize doors and central hall, remote control bedroom drapes. Located in Amarado Estates in Wichita, Kansas. \$149,900. Call Beverly Giles at (316) 554-2846 or (316) 393-5737.

## VANS

1982 Dodge Van, manual transmission with Ricon wheelchair lift, side mount, s-series. Runs well. \$2000. Call Lonnie at (620) 662-1373 or (620) 727-4726 or email midgee@swbell.net.

1995 Ford Club Wagon with Braun wheelchair lift that has 97,000 miles. Call (308) 832-2774.

Silver Ford Windstar 1996 Conversion Van: 34,000 miles with lift and power transfer seat. \$18,000. Call Jim Pence (316) 260-5660.

## WHEELCHAIRS

2003 Invacare Storm Series TDX 3 Wheelchair with 300 lbs. capacity. Seat raises and tilts with head rest, tight turning radius and more. Used 4 weeks. Call (816) 453-2576 and leave a message.

Leisure Lift Power Wheel Chair like new. Call Marvette Netherland at (913) 287-5645.

Reclining Quickie Wheelchair with headrest, elevating leg rests, removable arm rests, gel cushioned seat. Call Angela at (620) 763-2621 or email angela@ckt.net.

Red, motorized Pronto M6 with elevating leg rests, adjustable foot plates and arm rests, and headrest for \$3,500. Call (417) 732-6385.

Jazzy Red Electric Wheelchair Model 1143 20" chair, custom personal back - tall, 18 x 17 Jay 2

deep contour leg cushions, removable arm rest, elevating leg rests, adjustable foot plates. Used sparingly for 6 months. Paid \$8,000, asking \$4,000. Call Shirlee at (402) 393-5680.

Invacare Tilt and Recline System wheelchair with tray and head rest pads. Call (308) 832-2774.

Pride Jet 7 Motorized Wheelchair never used. 16.5" turning radius. Call (913) 287-7751 or (816) 507-3728.

## INDOOR ELEVATOR

Ram Thrust-T-Lift vertical wheelchair lift, height 142", maximum travel of 120". TTL control wall extension, solid end wall, keyed upper gate 42", adjacent access, carriage gate with interlock 54". Paid \$7,000; any reasonable offer considered. Call Diana at (913) 909-3777.

## CHAIR GLIDES

Two chair glides for sale. Each can be adapted to fit stairs from 6-12 steps. Good condition. Local company that can install. Call Cheryl at (816) 392-8597.

## PLATFORM LIFTS

Access Industries Indoor/Outdoor Vertical Platform Lift, Model PLS 96. Used less than one year indoors, 750 lbs. capacity. \$5,500 - does not include installation. Call (314) 374-4480.

## CHAIR LIFTS

Golden Lift Chair, neutral beige color, nearly brand new for \$300.00. Call 402-496-7672. ChamberLift 2000 Patient Lift System. Call (308) 832-2774.

## MISCELLANEOUS

Geomat Hospital Bed Mattress for \$75.00 and a Geomat pressure reduction mattress overlay for \$25.00. Please call (402) 496-7672.

### INCLUSION IN THE DIALOG IS NOT AN ENDORSEMENT FOR THESE PRODUCTS AND SERVICES.

If your item has also been sold or if you would like to place a new ad. Contact Kalista at 913-648-2062, ext. 222 or ktrombly@alsa-midwest.org

The Chapter is requesting a typewriter in good working condition for the Kansas City ALS office. Please call Sarah Tucker at (913) 648-2062, ext. 202.



The Chapter received 274 responses to the Candlelight Mailing. Thanks to all who participated. Donations are still being accepted. Please contact the office nearest you.

Phone Numbers & Email Addresses Are in the Box to the Right →



### EMAIL ADDRESSES AND PHONE EXTENSIONS TO BETTER SERVE YOU:

#### Directors

Kansas City (913) 648-2062

**Beckie Cooper, Ext. 210**  
*Executive Director*

bcooper@alsa-midwest.org

**Sally Dwyer, Ext. 212**

*Program Director*

sdwyer@alsa-midwest.org

**Mary Lu Euler**

*President*

info@alsa-midwest.org

#### Patient Services

Kansas City (800) 878-2062

**Linnea Brandt, Ext. 206**

lbrandt@alsa-midwest.org

**Nancy Lindquist, Ext. 204**

nlindquist@alsa-midwest.org

**Sarah Tucker, Ext. 202**

stucker@alsa-midwest.org

Nebraska (866) 762-6361

**Melissa Ramming**

mramming@alsa-midwest.org

Springfield (888) 386-1200

**Paul Blackwell**

pblackwell@alsa-midwest.org

Wichita (800) 553-9056

**Jean Haley**

jhaley@alsa-midwest.org

#### Fundraising

Kansas City (913) 648-2062

**Zee Peters, Ext. 221**

zpeters@alsa-midwest.org

Nebraska (402) 991-8788

**Steven Langan**

slangan@alsa-midwest.org

Springfield (417) 886-5003

**Valerie Gustin**

vgustin@alsa-midwest.org

Wichita (316) 612-0188

**Kathleen Wille**

kwille@alsa-midwest.org

**Chapter Website**  
www.alsa-midwest.org  
**National Website**  
www.alsa.org

### In Memoriam

We send our sympathy and support to the families and friends of those who have recently died after battling ALS.

Billy Lowrance

William H. Curry, Jr.

Jean Stargell

Mary Jane Sanders

Orene Renie Edmonds

David Stone

Marilyn Skoumal

Freda Strampe

### Memorials

Thanks to the families of the following for designating our Chapter for donations:

William H. Curry, Jr.

David Stone

Billy Lowrance

Freda Strampe

Mary Jane Sanders

Esther Juanita Vierling

# THE DIALOG

Keith Worthington Chapter  
8340 Mission Road, Suite B-4  
Prairie Village, KS 66206

Address Service Requested

Non Profit Org.  
U.S. Postage  
**PAID**  
Shawnee Mission, KS  
Permit No. 1249

## 8 • THE DIALOG

J U N E 2 0 0 5

### June Support Group Dates

1	Jefferson City	1:30 p.m.
1	Hutchinson	2:00 p.m.
2	Wichita	7:00 p.m.
14	Springfield	6:30 p.m.
7	Kansas City Evening SG	7:00 p.m.
9	Omaha	7:00 p.m.
10	Kansas City Caregivers SG	12:30 p.m.
15	Branson	1:30 p.m.
15	Kansas City Day SG	2:00 p.m.
16	Salina	7:00 p.m.
18	Wichita Caregivers	11:00 a.m.
22	Joplin	1:30 p.m.
27	Topeka	3:00 p.m.
27	Columbus	6:00 p.m.

### Support Group Locations

<p><b>KC Evening SG</b> 2nd Presbyterian Church 55th and Oak</p> <p><b>KC Day</b> Turning Point 8900 State Line, Ste. 240</p> <p><b>KC Caregivers/ Survivors SG</b> ALS- Must RSVP 8340 Mission Road, Ste. B4</p> <p><b>Wichita, KS Caregivers SG</b> ALS Office 526 S. Market Street</p> <p><b>Wichita, KS SG</b> Grace Presbyterian Church 5002 East Douglas</p> <p><b>Hutchinson, KS SG</b> Grace Episcopal Church 20<sup>th</sup> &amp; Main</p> <p><b>Topeka, KS SG</b> Shawnee Co. Public Library 1515 SW 10<sup>th</sup> Avenue</p>	<p><b>Salina, KS SG</b> Home of Nancy Persinger 409 Kirwin, 785.825.1833</p> <p><b>Omaha, NE SG</b> St. Pius X Parish Center 6905 Blondo Street</p> <p><b>Columbus, NE SG</b> Trinity Lutheran Church 2200 25<sup>th</sup> Street, Fireside Room</p> <p><b>Springfield, MO SG</b> Cox Medical Center South 3801 South National Ave.</p> <p><b>Jefferson City, MO SG</b> Southridge Baptist Church, 1815 Vieth Drive</p> <p><b>Branson, MO SG</b> Faith Lutheran Church 221 Malone Street</p> <p><b>Joplin, MO SG</b> South Side YMCA 3404 McIntosh Circle</p>
--	---

With Offices in the Following Cities, Contact the Office Nearest You!

<p><b>Kansas City</b> Linnea Brandt &amp; Nancy Lindquist (800) 878-2062</p>	<p><b>Nebraska</b> Melissa Ramming (866) 762-6361</p>	<p><b>Springfield</b> Paul Blackwell (888) 386-1200</p>	<p><b>Wichita</b> Jean Haley (800) 553-9056</p>
--	---	---	---